

# Disabled children's services in England

Information for families

Incorporating The Lady Hoare Trust

### Introduction

Local authorities have a responsibility to help families with disabled children. Many children have additional needs and disabilities, and some are more severely affected than others. Some disabled children and their parents will need practical support at home. This guide explains your right to get the support you need from your local authority through departments like social services, sometimes known as 'children with disabilities teams' or 'children's services'. The way local authorities work is changing at the moment and here we explain some of the changes you can expect to see.

#### **Contents**

Duties of social services	3
What is an assessment?	4
What services can be provided?	6
Charging for services	10
Common Assessment Framework	11
Direct payments	12
Making a complaint	13
Local Government Ombudsman	15
Taking legal action	16
Tips for attending meetings with social services	16
Frequently asked questions	17
Changes to services in England	22

#### **Duties of social services**

Social services departments of local authorities are responsible for arranging support for disabled children and their carers. You have a right to have your child and family's needs assessed by social services. Duties of social services to disabled children and their families include:

- providing a social worker service
- maintaining a register of disabled children
- providing information about services which may be available
- assessing the needs of disabled children and their carers
- providing a range of services to meet these needs.

Social services departments have a general duty under Section 17 (10) of the Children Act 1989 to safeguard and promote the interests of 'children in need'. The law recognises disabled children as being in need.

## Children in need are defined as children who are under 18 years of age and:

- are 'unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development without the provision of services by a local authority', or
- whose 'health or development is likely to be significantly impaired or further impaired without the provision of such services by a local authority', or
- are 'disabled'



Section 17 (11) of the Children's Act states that a child is disabled if they:

- are blind
- deaf, or
- non-verbal, or
- suffer from a `mental disorder of any kind', or
- are 'substantially and permanently handicapped by illness, injury or congenital deformity, or such other disability as may be prescribed'.

This part of the legislation can be found at: http://www.legislation.gov.uk/ukpga/1989/41/section/17.

A child in need is entitled to an assessment from the social services department. This assessment will set out the services that are considered necessary. An assessment is important because it can lead to a number of services being provided, like practical help in the home and short breaks.

#### What is an assessment?

An assessment is the process social services use to gather information about your child and family, so they can make a decision about what help you may need. The process for carrying out an assessment is contained within the Assessment Framework. Not to be confused with the Common Assessment Framework, the Assessment Framework is statutory guidance which the local authority must follow, including the timescales

In most cases an initial assessment is carried out, which might be as simple as a conversation over the phone. This helps social services work out whether a core assessment (an in-depth assessment) should be carried out.

Timescales given to social workers indicate that the initial assessment should be completed within a maximum of ten working days. The core assessment should not take longer than 35 working days.

### Getting information about the assessment

Beforehand, you should be told how the assessment will be carried out and be given information about what services are available, not just those which are provided by social services departments (for example, a local playscheme).

It should be a needs-led assessment It is very important to remember that the starting point of an assessment of your child should be their needs, regardless of whether services exist to meet them. Social services should assess your child in an open way and the assessment should focus on the circumstances of both your child and the rest of the family. As well as your child's disability and health needs, social services should also consider other aspects of your child's life, for example, education and religious or cultural needs.

#### What to expect at an assessment

The social worker will usually come to your home to talk to you. They should ask you for information about your child, for example, sleeping patterns, eating habits, how your child communicates, what activities they enjoy and whether you have any other children to look after.

The government has consulted on replacing nationally prescribed timescales for assessments (10 days and 35 days). Instead local authorities (LAs) will set their own frameworks for assessment. They are also seeking to remove the distinction between the initial and core assessments. The government has been working with eight local authorities to test this, including Cumbria, Knowsley, Hackney and Westminster, Wandsworth, Islington, Hammersmith and Fulham, and Kensington and Chelsea.

Whatever the outcome of the consultation, timeframes for the completion of the assessment must be timely and transparent to children and families. Local frameworks must be published publicly and the LA can be held accountable.

Don't be worried about asking for clear information about the focus of the assessment and what services are available. But do remember that the assessment should be **needs-led** and not based on services already available.

Preparing for a core assessment

It can be useful to make a list of questions before you meet, and you are entitled to have a friend or advocate there with you. The social worker may also want to speak to your child's health visitor, doctor or school to help them get a full picture of their needs.

#### How do I request an assessment?

Many social services departments have 'children with disabilities' teams. You should find the number in the telephone directory under the name of your local authority (LA), social services or children's services, or call our freephone helpline for information. You can also ask your GP, health visitor, community nurse, paediatrician or voluntary organisation to contact social services on your behalf. You may also find information on your council's website.

If you're unclear what LA you come under visit https://www.gov.uk/applyneeds-assessment-social-services. Your local Family Information service can also advise: http://findyourfis.daycaretrust.org.uk/kb5/findyourfis/home.page.



#### **Combining assessments**

The Children Act also says that various assessments can be combined, for example an assessment under the Education Act 1996 or the Chronically Sick and Disabled Persons Act 1970. This means, for example, that if your child's special educational needs (SEN) are being assessed, then social services should assess your child's needs under the Children Act at the same time.

Alternatively, call our freephone helpline for information.

It's a good idea to put your request in writing and to keep a copy of your letter or email. The request doesn't need to be detailed but should include:

- your name and address
- details of who is in your household, including any other children
- a brief description of your child's disability
- what kind of extra help your child needs
- whether you need help urgently.

## What if an assessment has been carried out in the past?

When services are already being provided the assessment should be reviewed regularly. But if your circumstances have changed, you can ask for a re-assessment or review in the same way as above.



What if I'm refused an assessment?

If your child is disabled and in need of services, you can't legally be refused an assessment. Consider making a complaint if this happens – see page 13, for more information. Also, if you need help urgently, you can ask for services to be put in place straight away without waiting for the outcome of an assessment. Advice on challenging a refusal to assess your child's needs can be found at http://www.edcm.org.uk/media/8269/assessment\_letter.pdf.

#### Your needs as a carer

The Carers (Recognition and Services)
Act 1995 means that parents can ask
for a carer's assessment. The carer's
assessment focuses on you as a parent
and your needs. Social services should
discuss issues like the help your child needs
and whether there is anyone else who
helps, or if you are your child's only carer.

The carer's assessment should also consider your well-being, including health and safety

issues, and important commitments like relationships and employment.

#### Why get a carer's assessment?

The aim of a carer's assessment is to give you a chance to tell social services about the things that could make looking after your child easier for you. This may result in getting services or direct payments to meet your own assessed needs.

The Carers (Equal Opportunities) Act 2004 requires local authorities to tell carers about their rights to an assessment. The Act also makes sure that work, education and leisure opportunities are considered when you're being assessed.

The 'Carer's assessment guide' contains further advice and is available from Carers UK. Call CarersLine on 0808 808 7777 or visit www.carersuk.org/help-and-advice/practical-help/care-and-support/carers-assessment

## What services can be provided?

#### After the assessment

After social services have carried out an assessment and reached a decision about whether your child is 'in need', they will consider which services are required.

They may decide there is no need for services, which could result in your case being closed with no further action taken. If you disagree with this decision you can challenge it using the local authority's complaints procedure. Or they may decide that there is a need for services and these should be provided.

## What services can I expect for my child and family?

Services for disabled children are available under Section 2 of the Chronically Sick and Disabled Persons Act 1970 and under the Children Act 1989.

The Chronically Sick and Disabled Persons Act sets out what kind of help should be provided. Under this Act, the duty to provide services is to the individual disabled child and does not extend to other members of the family. These services are:

- practical assistance in the home, like help with the personal care of your child, for example help with getting in and out of bed
- equipment for a recreational need, like a TV, radio or computer
- leisure facilities (this could mean outings or a placement at a day centre), or
- education facilities (this could mean home-based education or funding for the personal care requirements of students so they can study)
- travel and other assistance, like travel to and from a day centre
- home adaptations and disabled facilities, for example fitting handrails or hoists
- holidays
- meals
- telephone equipment.

The Children Act 1989 sets out a range of support services which should be available. This includes the right to permanent or temporary residential accommodation, if your child needs it. It forms the legal basis for residential short breaks. If your child needs this service,

## "A break - it makes us both feel human again!"

**Alexis** 

then it should be provided. If there are no suitable facilities locally, your local authority can look outside its own area.

There are other services listed in the Children Act. Here are some examples:

- occupational, social, cultural or recreational activities
- home help
- assistance to enable your child and family to have a holiday
- advice, guidance or counselling
- · travel assistance.

Under the Children Act 1989 local authorities have a general duty to make a range of services available to help children in the area. Importantly, the Act allows social services to provide help which will benefit other family members, like siblings and other carers.

#### **Short Breaks**

The Children and Young Persons Act 2008 amended a section of the Children's Act 1989. The amendment introduced The Breaks for Carers of Disabled Children Regulations 2011 and came into force in April 2011.

The Regulations require local authorities in England to set out a range of services which will help parents of disabled children continue to provide care more effectively. The range of services must include:

- day time care in the homes of disabled children or elsewhere
- overnight care in the homes of disabled children or elsewhere
- educational or leisure activities for disabled children outside their homes or elsewhere
- services available to assist carers in the evenings, at weekends and during the school holidays.

By 1 October 2011 authorities must have prepared a statement for carers which sets out the range of services above, eligibility criteria, and how these services are designed to meet the needs of carers in their area. Also, the statement must be published and made available on their website, reviewed, and consider the views of local people.

"We were told time and time again: unless you were in crisis there was no support for us. Looking back, I think we were in crisis, but you don't like admitting it."

Amy

#### When should services be provided?

Services available under both the Children's Act and the Chronically Sick and Disabled Persons Act should be provided when there is an assessed need, and services are necessary to meet those needs. But in practice, most local authorities use 'eligibility criteria' to help them make this decision.

#### Eligibility criteria

There are many disabled children in an area who need help but social services have limited financial resources. Using 'eligibility criteria' for deciding who has a 'need' for services is a way they can prioritise, to make sure the people most in need get help.

The criteria are different from one authority to another and this means if you move to a different local authority area you may no longer qualify for the same help.

For example, one of the services listed under the Chronically Sick and Disabled Person's Act is 'holidays'. This doesn't mean every disabled child must be given a holiday each time they ask. There will be local eligibility criteria. It might say for instance, that holidays will normally only be given if a child has not had a holiday for five years and there is a risk of family breakdown if it's not given.

### When an assessment shows you meet the criteria

Once your child's assessed needs match the local eligibility criteria, the local authority has a duty to provide or arrange services to meet those needs.



In this example, if your child had not had a holiday for five years and you could show that your family was under such stress that family breakdown was possible, there would be an obligation to fund the holiday regardless of the local authority's financial difficulties.

However, the local authority can take its resources into account to decide how it will actually meet the needs. It might limit the type of holiday it provides, or it might arrange for another organisation to do so. It could even apply for a charitable grant to fund the holiday.

### When you don't meet the eligibility criteria

If the service is not actually assessed as a need (perhaps seen as only useful), or if it is assessed as a need but does not fit the local criteria, the local authority has no actual obligation to provide or arrange the service. They should still use their best endeavours to meet the need, for example by contacting a local charity or voluntary agency for help.

If the decision is that services aren't needed, or that you don't fit the eligibility criteria, you should be given clear reasons. This is to help in case you want to challenge the decision using the complaints procedures (see page 13).

#### Beware!

It is quite common to hear statements like, 'Our local authority no longer provides short breaks' or, 'We don't do carers assessments in this local authority.' These statements are unlawful and you should have good grounds for a complaint (see page 13).

In fact, the local authority should not put a blanket ban on any service and should always consider the needs of the individual child and family. Other families have challenged these statements in court and the courts have decided that a local authority can't 'unlawfully fetter its

discretion'. This means they must always be prepared to consider requests which don't fit into their eligibility criteria.

Using the holiday example from earlier, it would be illegal for a local authority to say, 'we never give holidays to children unless they have not had one for five years'. They can say, 'we don't usually give holidays' but they must always listen to any reasons you have about why you should be treated as an exception.

#### The care plan

Once the social worker has gathered enough information through the assessment, they decide which of your child's various needs can be supported by providing services. In many local authority areas a panel decides the package of services that may be offered. A care plan should then be agreed between social services and you and your family, to meet any identified needs. The plan should give details of:



- what services will be provided
- for how long the services are needed
- what the local authority plans to achieve by providing the services
- what each person and agency is expected to do
- · date of the next review.

Importantly, the care plan should be reviewed regularly to make sure any services remain appropriate.

#### **Charging for services**

#### Will I have to pay for any services provided?

Local authorities do have the power to charge for services they provide under the Children Act 1989 and the Chronically Sick and Disabled Persons Act.

In England, each local authority will have its own charging policy and it is usually your income and savings as a parent that are taken into account, rather than your child's. You should not be asked to pay more than you can afford.

When a child reaches 16 years of age, they are assessed in their own right. This means it should be their ability to pay which is taken into account and not vours.

#### When should I not be charged?

If you get Working Tax Credit, or Child Tax Credit (paid at a rate above the family element) or Income Support or income-related Employment and Support Allowance, you should not be charged for Children Act services. You should also not be charged for advice, information and counselling services, regardless of your financial situation.

### Do I have to pay for services provided to me as a carer?

Services for carers of disabled children are normally provided under the Children Act and the same charging rules above apply.

### What if I can't afford to pay the assessed charges?

If you feel you are being charged wrongly, or at a level which is more than you can reasonably be expected to pay given your circumstances, you can ask for the charges to be reduced or waived completely. If you're still unhappy with the amount you've been asked to pay you can make a formal complaint (see page 13).

If you have any further questions about charging, call our freephone helpline.

## **Common Assessment Framework (CAF)**

The CAF is another way that children and families can be assessed and receive services. It is important to note that this process does not replace the detailed assessments under the Children's Act described above. The duty to assess under the Children's Act remains.

Introduced under the Children Act 2004, in England all local authority areas were expected to implement the 'Common Assessment Framework' (CAF) between April 2006 and the end of 2008.



The CAF can be used if you, or someone who works with your child, would like them to receive extra support. It will help to identify your child's additional needs, and other workers required to support your family.

If you and your child agree, a worker will ask you both some questions to find out what help and support you might need. This information is recorded on a simple form. Once you're satisfied with the information on the form you'll be given a copy of it. Based on the information you both provide, everyone who can help your child should work together to provide the support they need.

A 'lead professional' will be appointed who should keep you informed, listen to your views and support you. They will also co-ordinate all the services supporting your child. You should be allowed a say in who should be the lead professional.

Further information on how the CAF operates in your area should be available from your local authority and usually on their website.

#### **Direct payments**

#### What are direct payments?

Local authorities can give payments, instead of services, to allow disabled people and carers to buy in the services they've been assessed as needing. Any payments you receive must only be used to pay for these services.

Direct payments are there to promote the independence of parents and disabled children who would like to manage their own social care needs. If your child is under 16 years of age, direct payments will usually be made to you as their parent. When a child turns 16 they can receive payments in their own right, to allow them to buy in the services they've been assessed as needing.

In the past you couldn't insist on direct payments. But now a request should only be refused in very limited circumstances.



#### How much are direct payments?

The amount you receive should be enough to allow you to meet all the costs involved in arranging services that social services have agreed to help with. This should include any tax and national insurance you might have to pay if you employ someone, as well as the cost of a criminal records check.

Social services will usually deduct an amount from the payments, equivalent to what you would have been charged if they'd arranged the services. Or they may make the payments in full and ask you to reimburse them any assessed charge.

#### Further information about direct payments

Contact a Family has a guide Getting direct payments for your disabled child. Call our freephone helpline for a copy or visit the resources section of our website to download it at www.cafamily.org.uk.

#### **Personal Budgets**

Instead of services some families may be offered personal or individual budgets by their local authority. The aim is to give carers and disabled people control of how they arrange and buy services to meet their own needs. The budget can be allocated for equipment and adaptations as well as for meeting social care needs.

Not to be confused with direct payments, it is important to understand that a personal or individual budget is an amount allocated by the council but not paid to the carer or the disabled person needing services. Whereas direct payments are paid in order to meet a specific assessed need.



Another very important difference is the way the amounts are arrived at. Direct payments are offered following an assessment of needs, and the amount paid should be enough to pay for the service. With personal or individual budgets the amount you get is determined by a system, often using points, to indicate the level of services a disabled person may need. This is often referred to as a Resource Allocation System (RAS). Because of this method the outcome of the RAS may lead to a shortfall in necessary services and support. For this reason it is important to be aware that the legal duty to carry out assessments and provide services for eligible, assessed needs still remains.

Families have the right to decline the 'indicative amount' and personal budgets and can insist that their care package is provided by the local authority or via direct payments. For more information visit www.in-control.org.uk/support/support-for-individuals,-family-members-carers.aspx or call our freephone helpline.

#### **Making a complaint**

Under The Children Act 1989 'Representations Procedure (England) Regulations 2006' parents and carers can complain about:

- service quality or appropriateness
- delays in decisions being made or services being put in place
- how services are delivered (or not delivered) including the way complaints are dealt with
- the amount of help given, how frequently a service is provided, any changes made to services or how much you are asked to pay
- the attitude or behaviour of staff
- how eligibility and assessment criteria are applied
- a local authority policy which impacts on you or your child
- any aspect of the assessment, reviews or care management.

#### Who deals with a complaint?

Each local authority has a 'designated officer' who receives all complaints, called the complaints manager. They don't have to handle all stages of the complaint but are responsible for administering the scheme to make sure complaints are dealt with swiftly and effectively.

#### How quickly can I expect a complaint to be dealt with?

Time scales are summarised below.

#### Stage 1 – Local resolution

You should bring your concerns to the attention of the person providing the

services locally. The local authority should consider mediation at this stage, and all other stages.

They should make a first attempt to resolve matters within 10 working days. This can be extended by another 10 days, for example if an advocate needs to be appointed.

If the matter isn't resolved, or if there is agreement for an investigation to take place, then the complaint should go to Stage 2. If you wish the complaint to go to this stage you can request this orally or in writing.

#### **Summary of Stage 3 time limits**

Action: Time frame:	You request a Review Panel Up to 20 working days after receipt of the Stage 2 decision
Action: Time frame:	Complaints manager acknowledges request Within two working days
Action: Time frame:	Complaints manager appoints a Chair and confirms attendees and content of the panel papers Within 10 working days of your request for Review Panel
Action: Time frame:	Local authority agrees the other panellists and date for Review Panel Within 30 working days of your request for Review Panel
Action: Time frame:	Local authority circulates panel papers Within 10 working days of the date for the Review Panel
Action: Time frame:	Review Panel produces its written report (including any recommendations) Within five working days of the Review Panel meeting
Action: Time frame:	Relevant director issues their response Within 15 working days of receiving the Review Panel's report

The Ombudsman will decide whether the council has done something wrong which has directly affected you and caused you an injustice.

#### Stage 2 – Investigation

The local authority should arrange an investigation that produces a report and a decision within 25 working days (or within an extended period of 65 working days where a response is not feasible within 25 days). If the matter is still not resolved then you can ask for a panel to consider your complaint. The investigation will be undertaken by a nominated complaints officer.

#### Stage 3 – Review Panel

The person making the complaint can ask for the matter to go to a Review Panel within 20 working days of receiving a Stage 2 decision. This is a meeting of three independent people who will consider the complaint and make recommendations. The process of holding a review panel must follow certain time limits. See box on page 14.

### Unhappy with the outcome of a Review Panel?

If, after a Review Panel has considered your complaint, the matter is still not resolved then you can take your complaint to the Local Government Ombudsman (LGO). You may be able to approach the LGO earlier – for more information see below.

You can find further information about complaints in government guidance, 'Getting the best from complaints - social care complaints and representations for children, young people and others' available at http://tinyurl.com/cc9oxlx.

#### Local Government Ombudsman

If you're not happy with the panel's decision then there are various other options, like taking the issue up with a local councillor or MP or complaining to the respective Local Government Ombudsman (LGO).

The Ombudsman can investigate complaints against principal councils (not town, parish or community councils) and certain other bodies. By law they must look for 'maladministration' by a council. Maladministration is a term which describes the actions of a government body which can be seen as causing an injustice. Examples include:

- delays
- incorrect action or failure to take any action
- failure to follow procedures or the law
- failure to provide information
- inadequate record-keeping
- · failure to investigate

- failure to reply
- misleading or inaccurate statements
- inadequate liaison
- inadequate consultation, and
- broken promises.

The Ombudsman will decide whether the council has done something wrong which has directly affected you and caused you an injustice. They won't investigate a complaint against the council simply because you disagree with it.

There are two LGO's in England. Each of them deals with complaints from different parts of the country. For further information visit:

www.lgo.org.uk/contactus or call the LGO Advice Team on 0300 061 0614.

#### **Taking legal action**

#### Judicial Review

If your complaint is very urgent and you can't wait for the complaints procedure to resolve the matter, you can apply to the courts for a Judicial Review. Judicial Review is a procedure where the High Court looks at the way a decision was reached to see if it was legally correct.

You can also apply for Judicial Review if you have exhausted the complaints procedure and are still unhappy with the outcome. To do this you will need legal assistance.

If you have a low income you may qualify for legal aid. Also, some solicitors offer a free first interview.

#### Tips for attending meetings with social services

- Be prepared. For example, you might want to have visited a school or a residential home if you're planning to talk about placements.
- Keep copies of everything like letters you've written about your child to the authorities, as well as those they send you. Keep everything in a file, making sure you read everything you think might be relevant before the meeting to refresh your memory.
- Make notes. It's easy to forget something so having a few notes handy at a case conference will help to make sure you cover all the points

- you want to make. Listen to what the professional workers have to say and make notes of what is said.
- Take someone with you. If you have a partner, make sure you both attend the case conference. If that's not possible, or you are a single parent, take a friend or someone from a local support network.
- Don't be frightened to ask if you don't understand what's being said; ask questions until you do.
- Keep calm. Don't lose your temper if things are going wrong. Try and give reasoned, counter arguments.
- Follow up. Compare notes and draw up a summary of the main points made at the meeting, what was agreed, and what still needs to be agreed.

Further information about help with legal costs can be found on GOV.UK website, at http://tinyurl.com/6cxvjro.

For help with finding a specialist legal advisor visit https://www.gov.uk/legal-aid. Or call our freephone helpline for advice.

## Frequently Asked Questions

My social worker said I should put my disabled child on a register of children with disabilities. What does this mean? Social services have an obligation to keep a register of children with disabilities. This isn't the same as the child protection register and doesn't suggest in any way that your child is at risk. You don't have to agree to your child's name being added to the register and it doesn't affect your entitlement to services.

A register allows social services departments to try and plan services for disabled children more effectively in their area. It is sometimes used as a way of getting relevant information to families so you might get a newsletter as a result.

## My daughter is disabled and I'm wondering if I can get a Blue Badge?

The Blue Badge Scheme is a UK arrangement of on-street parking concessions for disabled people. The badge can also be used in many European countries.

If your child has severe walking difficulties, is registered blind, has severe upper limb disabilities or receives the higher rate mobility



component of Disability Living Allowance, you may be eligible.

If you are a parent of a child who is less than two years old, you may apply for a badge for your child if they have a specific medical condition which means that they either:

- must always be accompanied by bulky medical equipment which cannot be carried around without great difficulty
- need to be kept near a vehicle at all times, so that they can, if necessary, be treated in the vehicle, or quickly driven to a place where they can be treated, such as a hospital.

You should apply to your local social services department.

Department of Transport guidance can be found at:

www.dft.gov.uk/publications/blue-badge-scheme-local-authority-guidance.

My son has ADHD and is also autistic. Social services won't assess my child, saying they can only help children with physical disabilities and they don't have any suitable services.

Under the Children Act 1989 a local authority has a duty to assess any child in need. See the definition of 'children in need' on page 3 of this guide. The definition includes a reference to someone who 'suffers from mental disorder of any kind'. Whilst this phrase is outdated this can include a wide range of conditions, including Asperger syndrome/ high-functioning autism, attention deficit hyperactivity disorder (ADHD) and attention deficit disorder (ADD) as well as impairments such as learning disability, mental illness and personality disorder. In light of this definition it would appear that social services have acted incorrectly by refusing your request for an assessment and therefore failing in their general duty to provide a range of services for all disabled children. But you should note that they're also allowed to set

eligibility criteria for specific services which could mean that your child won't qualify for a service because he doesn't meet the criteria. If this is the case and you're unhappy about this decision, then you can make a complaint using the local authority complaints procedure. See page 13.

Can my social worker advise me on which benefits my family are entitled to? Social workers do have a duty to provide advice and guidance. They should explain to you what benefits are available and make sure you're getting the benefits you're entitled to.

However, most social workers are not benefits experts and they may rely on the local authority's welfare rights service or similar advice agency to help you. They may also direct you to a voluntary organisation like the Family Fund for further help. Advice about entitlements can also be found within a range of guides we produce, available from our freephone helpline. Additionally, helpline



advisers can answer benefit enquiries and refer to our welfare rights team for further specialist advice if necessary.

Due to the cuts, I'm worried that I will lose help the council provide with getting my daughter ready for school in the mornings. I'm disabled too and couldn't manage without this.

Your local authority must continue to provide the service as long as you continue to meet the criteria you were assessed against. Additionally the authority cannot take its resources into account if you would be left at severe physical risk if the help was not provided.

However, the local authority can take its resources into account when setting criteria for services. This means they may choose to introduce new stricter criteria which could make it harder for you to access the same level of help. Even with the introduction of new criteria they can only reduce or withdraw a service after carrying out a re-assessment of needs and you fail to meet that new criteria. A decision to withdraw or reduce a service in this way may still be challengeable using the complaints procedure or taking legal action. Contact our freephone helpline for further advice.

### Do I have a right to see my child's records?

Under the Data Protection Act 1998 professionals and agencies have a duty not to disclose information about disabled children and their families without the consent of the 'subject'. This applies to children as well as adults provided that, if they are under 16 years of age, 'they have the ability

to understand the choices and their consequences'.

Even though there's a duty not to disclose without the child or young person's consent, the public body concerned (for example, the health service or local authority) still have the discretion to allow access to the information. In most cases parents should have no difficulty seeing their child's records.

Guidance also says that advocates should be given access to relevant information about the person they're representing. Our freephone helpline can give you further advice about access to personal records.

## Can I use direct payments to employ my sister-in-law who lives with me to look after my son?

The 2003 Direct Payments Regulations make it that clear that a direct payment should not be used to employ a spouse, partner or close relative living in the same household as the disabled person.

However, employing a close relative may be possible if this is the only effective way to meet a child or young person's needs. For example, if a child has complex communication needs or specific cultural needs then it may be acceptable to employ a family member who could meet those needs.

#### I'm finding it very difficult to cope and need help at home, but I'm scared that if I contact social services they'll take my children away.

Unfortunately, there are many parents who feel that needing help will lead to social services taking their child away. Some even feel that a request for help is a sign of weakness or bad parenting. For this reason we understand that some families will not seek help.

It's important to understand that while social services have specific duties around child protection issues and protecting vulnerable children from harm, they also have duties and responsibilities to support families. This means where possible keeping the family together.

Social services should respond to your situation by carrying out an assessment to identify your needs. If you like you can also ask for a separate assessment as a carer. Either way, this should lead to a recognition of your needs and the practical support you're looking for to help ease the situation at home.

Some parents get regular breaks which allow them to spend time either with their other children or alone, so they can recharge their batteries. Spending time away from your disabled child may also help foster a sense of independence. This may be particularly helpful with transition to adulthood, as they grow up.

If you're still concerned about approaching social services, you may find it helpful to contact a voluntary organisation for support and advice. They may be able to support you in your request for help or tell you

about other services which aren't linked to social services. Contact our freephone helpline for further information.

My husband and I are asylum seekers and care for our severely disabled daughter. We can't claim any benefits and we're not allowed to work. Instead we receive asylum support from the UK Border Agency (UKBA). We're finding it very difficult to lift our daughter in and out of the bath and onto the toilet. She also needs a wheelchair - without one we can't take her anywhere. Are we entitled to any extra help?

The UKBA are responsible for maintaining you, your husband and your child. They are responsible for providing for a child's 'essential living needs'. This means the needs of 'an ordinary child or adult with no special peculiarities or disabilities'.

Although section 122 (5) Immigration and Asylum Act 1999 states that local authorities cannot provide 'assistance' under section 17 of the Children Act 1989 to a child whose parents are receiving UKBA asylum support, this doesn't prevent them from providing support to a child who is disabled. Any needs that go beyond 'essential living needs', such as the needs arising from a child's disability, should be provided for by the local authority.

Under the Children Act 1989 the local authority can provide further support and services for your daughter's needs as a disabled child. If UKBA asylum support is inadequate you can approach your social services department for help.



It is important to seek further clarification about your rights to make sure you don't jeopardise your status and current support. You may find, for example, that getting practical help from another source to meet another need could affect the asylum support you get from UKBA. Call our freephone helpline for further information on specialist sources of advice.

I am a student from overseas, living with my wife and disabled child. Because of our immigration status we've been told we have `no recourse to public funds'. What does this mean? Most people coming to stay in the UK under the immigration rules are expected to be able to house and support themselves financially, without having to rely on public funds or state support. This is what is meant by 'no recourse to public funds'

In reality this means you're not usually allowed to claim benefits like Income Support, Housing and Council Tax benefits, Disability Living Allowance and tax credits.

Also, you're not usually allowed to apply for local authority housing.

For the purposes of immigration rules 'public funds' does not include NHS treatment, state education or help from social services, for example under the Children Act 1989. If you're not clear about your rights it's very important to seek specialist advice. If you don't, it could affect your status and right to remain in the UK.

The Contact a Family freephone helpline can provide limited advice and assistance on immigration matters, including advice on rights to entitlements. But we can't help with more complex issues like challenging a failed application for asylum or advising on deportation.

#### **Changes to services in England**

From 2014, the Children and Families Bill proposes changes to the law on how children and young people with special educational needs and disabilities are identified and get services. This follows the SEN and disability green paper consultation.

Key recommendations from the paper include a single assessment and the right to personal budgets, which will replace SEN statements and learning difficulty assessments for older children. This will be available to children and young people up to age 25. These and other key recommendations are currently being tested in certain parts of England and will therefore only affect a relatively small number of families. In the meantime current legal rights to statements and assessments remain in place for all families including those families who live in the pathfinder areas.

The government is also looking at the law and funding of adult social care. As well as dealing with carers rights the draft Care and Support Bill will look at transition from child to adult services.

For further information on both bills call our freephone helpline.

If we can't give the help you're looking for, we should be able to suggest where to get help in your area.

Call our freephone helpline for information about specialist immigration advice services on 0808 808 3555 or email helpline@cafamily.org.uk



Written by Jesslyn Parkes

#### **Social networking**

Contact a Family is on Facebook and Twitter. Join us at:

#### **Facebook**

www.facebook.com/contactafamily

#### **Twitter**

www.twitter.com/contactafamily

#### **Podcasts**

You can download podcasts from our website at: www.cafamily.org.uk

#### **Videos**

You can watch videos on our YouTube channel at:

www.youtube.com/cafamily

## Getting in contact with us

Free helpline for parents and families **0808 808 3555** 

Open Mon-Fri, 9.30am-5pm Access to over 170 languages

#### www.cafamily.org.uk www.makingcontact.org



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Fax **020 7608 8701** Email **info@cafamily.org.uk** Web **www.cafamily.org.uk** 

## Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. Titles available include:

- The tax credits guide (UK)
- Fathers (UK)
- Understanding your child's behaviour (UK)
- Holidays, play and leisure (UK)
- Grandparents (UK)
- Siblings (UK)
- Special educational needs
- Preparing for adult life and transition
- Getting direct payments for your disabled child

A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

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